## AMENDED IN SENATE AUGUST 2, 2010 AMENDED IN SENATE JUNE 24, 2010

CALIFORNIA LEGISLATURE—2009-10 REGULAR SESSION

## ASSEMBLY BILL

No. 70

## **Introduced by Assembly Member Norby**

December 12, 2008

An act to add and repeal Section 66019.7 of the Education Code, relating to public postsecondary education, and declaring the urgency thereof, to take effect immediately.

## LEGISLATIVE COUNSEL'S DIGEST

AB 70, as amended, Norby. Public postsecondary education: genetic testing.

(1) Existing law, known as the Donahoe Higher Education Act, sets forth the missions of the various segments of public postsecondary education in this state. The segments of public postsecondary education in this state are the California State University, the University of California, and the California Community Colleges. The provisions of the Donahoe Higher Education Act apply to the University of California only to the extent that the Regents of the University of California act by resolution to make them applicable.

Existing law, known as the Protection of Human Subjects in Medical Experimentation Act, prohibits a person from being subjected to any medical experiment unless the informed consent of that person is obtained. The act specifies the potential civil and criminal liability of a person who is primarily responsible for conduct of a medical experiment and who negligently allows the experiment to be conducted

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without a subject's informed consent or who willfully fails to obtain informed consent.

This bill would add to the Donahoe Higher Education Act a provision prohibiting requesting the California State University—from, and requesting and the University of California to refrain from, making an unsolicited request, as defined, to an enrolled or prospective student of that segment for a DNA sample for the purpose of genetic testing. The bill would specify that it does not prohibit a licensed health care provider in a university facility from performing genetic testing and counseling in the course of a patient's medical care.

The bill would require the University of California and the California State University to report, on a quarterly basis, in writing, the total amount of any expenditures, irrespective of source, the university makes in order to make an unsolicited request or requests to any enrolled or prospective student of that segment for a DNA sample for the purpose of genetic testing pursuant to legal judgments or settlements resulting from violations of the informed consent requirements of the Protection of Human Subjects in Medical Experimentation Act or a specified federal regulation, or both, relating to unsolicited requests for DNA samples. The bill would require that the first of these quarterly reports be submitted to the Controller, the Governor, and the Legislature on or before January 1, 2011, and include all university expenditures for this purpose that have occurred prior to the date of the report.

The bill would require the Controller to revert to the General Fund an amount equal to the amount of any expenditures reported pursuant to the bill from any unencumbered moneys that have been previously appropriated from the General Fund to the University of California *and the California State University*. The bill would require that subsequent quarterly reports be submitted on or before January 1, April 1, July 1, and October 1 of each year while this provision is operative.

These provisions would be repealed on January 1, 2015.

(2) This bill would declare that it is to take effect immediately as an urgency statute.

Vote:  $\frac{2}{3}$ . Appropriation: no. Fiscal committee: yes. State-mandated local program: no.

*The people of the State of California do enact as follows:* 

1 SECTION 1. The Legislature finds and declares all of the 2 following:

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(a) The collection, testing, and storage of genetic material pose unique challenges to protecting individual privacy.

- (b) Recent research demonstrates that even seemingly anonymous genetic data can be used to identify individual research subjects.
- (c) The Protection of Human Subjects in Medical Experimentation Act (Chapter 1.3 (commencing with Section 24170) of Division 20 of the Health and Safety Code) requires that subjects receive substantial written and verbal explanations before they can provide informed consent.
- (d) Universities design programs to engage the student body and encourage broad participation, and students may feel coerced to participate in official activities involving widespread genetic testing.
- (e) The federal Government Accountability Office concluded in 2006 that genetic tests to inform dietary and nutritional choices "are medically unproven," "mislead consumers," and "do not provide meaningful information."
- (f) A student who voluntarily provides DNA to a public institution of higher education could suffer consequences later in life, if some future occurrence causes the confidentiality of the DNA sample to be compromised in some manner.
- (g) For example, in May 2009, a hacking attack at the University of California, Berkeley, compromised the security of the medical information of approximately 100,000 current and former students.
- SEC. 2. Section 66019.7 is added to the Education Code, to read:
  - 66019.7. (a) Notwithstanding any other law:
- (1) (A) The California State University is prohibited from, and the University of California—is are requested to refrain from, making an unsolicited request to an enrolled or prospective student of that segment for a DNA sample for the purpose of genetic testing. This
- (B) As used in this section, "unsolicited request" means a transmittal of materials designed to collect DNA to any person or entity without that person's or entity's prior express invitation or permission.
- (C) This section does not prohibit a licensed health care provider in a university facility from performing genetic testing and counseling in the course of a patient's medical care.

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(2) The University of California and the California State *University* shall report, on a quarterly basis, in writing, the total amount of any expenditures, irrespective of source, the university makes in order to make an unsolicited request or requests to any enrolled or prospective student of that segment for a DNA sample for the purpose of genetic testing. The pursuant to legal judgments or settlements resulting from violations of the informed consent requirements set forth in Section 24173 of the Health and Safety Code or Part 46 (commencing with Section 46.101) of Title 45 of the Code of Federal Regulations, or both, relating to unsolicited requests for DNA samples. The first of the quarterly reports required by this section shall be submitted to the Controller, the Governor, and the Legislature on or before January 1, 2011, and shall report all university expenditures for this purpose that have occurred prior to the date of the report. Subsequent quarterly reports under this section shall be submitted on or before January 1, April 1, July 1, and October 1 of each year while this section is operative. 

- (3) (A) The Controller shall revert to the General Fund an amount equal to the amount of any expenditures reported by the University of California pursuant to paragraph (2) from any unencumbered moneys that have been previously appropriated from the General Fund to the University of California.
- (B) The Controller shall revert to the General Fund an amount equal to the amount of any expenditures reported by the California State University pursuant to paragraph (2) from any unencumbered moneys that have been previously appropriated from the General Fund to the California State University.
- (b) (1) A report to be submitted pursuant to paragraph (2) of subdivision (a) shall be submitted in compliance with Section 9795 of the Government Code.
- (2) Pursuant to Section 10231.5 of the Government Code, this section is repealed on January 1, 2015.
- SEC. 3. This act is an urgency statute necessary for the immediate preservation of the public peace, health, or safety within the meaning of Article IV of the Constitution and shall go into immediate effect. The facts constituting the necessity are:
- In order to protect students of the California State University and the University of California from unsolicited requests to submit

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- to genetic testing prior to the commencement of the 2010–11 academic year, it is necessary that this act take effect immediately.